



Coordinated & Integrated Data Systems for Early Identification (CIDSEI)

Help Me Grow Forum

Content Session

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U.S. Department of Health
and Human Services
Centers for Disease
Control and Prevention





Disclaimer

The findings and conclusions of this report are those of the author and do not necessarily represent the official position of the Centers for Disease Control and Prevention



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Agenda



Introductions



Background of the CIDSEI Project



CIDSEI Project Coordination



Phase 1: Landscape Scan



Phase 2: Key Informant Interviews



Phases 3 & 4: *A Roadmap to Advance Family-Engaged Developmental Monitoring*

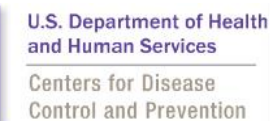


Next Steps and A Vision for the Future



Questions

Introductions



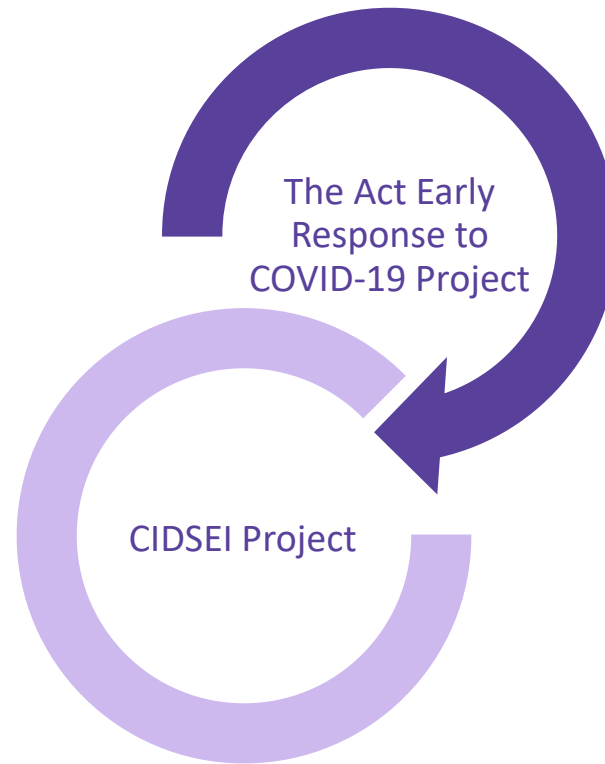
Meet the Team

Name	Organization
Betsey Howe Danielle Webber Harpur Schwartz	Association of University Centers on Disabilities
Cassandra Therriault Melissa Passarelli Noshin Ahmed Sarah Zucker Kimberly Martini-Carvell Dr. Paul Dworkin	Help Me Grow National Center
Stephanie Walchenbach Adam Hardy Sally Morris-Cote	HMG Implementation Experts
Kathy Houston	HMG North Texas

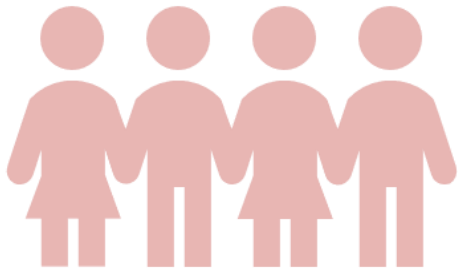
Background on the CIDSEI Project



Relationship of the CIDSEI Project to The Act Early Response to COVID-19 Project



Components of Early Identification



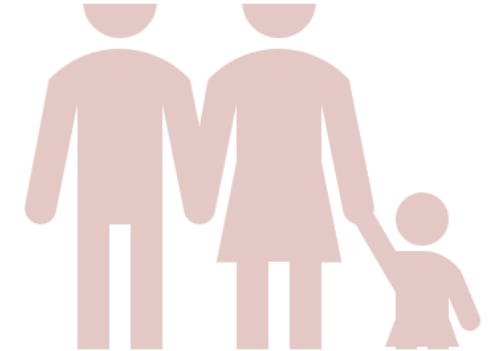
Parent-Engaged
Developmental
Monitoring



General
Developmental and
Autism Screening



Referral for Services



Receipt of Early
Intervention

Needs Assessment Findings

- Respondents were 43 Response Team leads and 349 partners from different early childhood programs (i.e., home visiting, Title V, Part C)
- Nearly all respondents (92.9%) reported involvement in a least one of the four components of early identification
- Many of the respondents indicated they did not have data to measure the impact of their work on early identification

Challenges for Data Collection

Need for a centralized data system

Lack of communication between programs

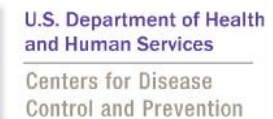
Lack of data sharing between and across programs

Why is Data Needed

- To prevent loss to follow-up
- To avoid duplication of services
- To relieve the burden on families for follow-up
- Program planning and evaluation
- To obtain child level data
- Improve timeliness of service delivery

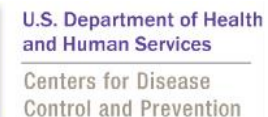


CIDSEI Project Coordination



The CIDSEI Project

- Funded during year 2 of the Act Early Response to COVID-19 project
- Cooperative agreement between the CDC and AUCD
- AUCD subcontracted with the Help Me Grow National Center (HMG National)
- HMG National brought in an implementation expert and HMG North Texas as a local affiliate
- AUCD and HMG National formed a national advisory committee
- HMG National utilized affiliate workgroups



CIDSEI National Advisory Committee

Name	Organization
Alexandra Goldberg	Healthy Starts Coalition of Florida
Anna Corona	AMCHP
Christopher Botsko	Altarum
Colleen Murphy	Early Childhood Connector at Start Early
Cynthia Tate	BUILD Initiative
Deepa Srinivasavaradan	SPAN Parent Advocacy Network, HMG New Jersey
Iheoma U. Iruka	Frank Porter Graham Child Development Institute
John Eisenberg	National Association of State Directors of Special Education
Julia Abercrombie	Centers for Disease Control and Prevention
Kathleen Hebbeler	SRI International
Kimberly Martini-Carvell	Help Me Grow National Center
Maureen Greer	IDEA Infant and Toddler Coordinators Association
Paul Dworkin	Community Child Health at CT Children's Medical Center

HMG Affiliate Work Group Members

Name	HMG Affiliate
Carmen Wagner, Sonya Sipos, & Tamar Ben Youseff	Alaska
Mong Thi Nguyen & Christine Smith	Sacramento, California
Rebecca Hernandez, Lacey Ginter, & Jacquely Norton	Orange County, California
Luz Rivera, Bethanne Vergean, & Kareena Duplessis	Connecticut
Taylor Bagwell, Jane Witkowski, & Tiffany Howard	South Carolina
Kathy Houston	North Texas
Tomas Caceres, Maddison DeGoff, Jodi West, Kali Ottesen, & Barbara Leavitt	Utah
Leslie Davis & Janet Kilburn	Vermont
Taz Barnes, Faith Mitchell, & Omotunde Sowole-West	Washington D.C.

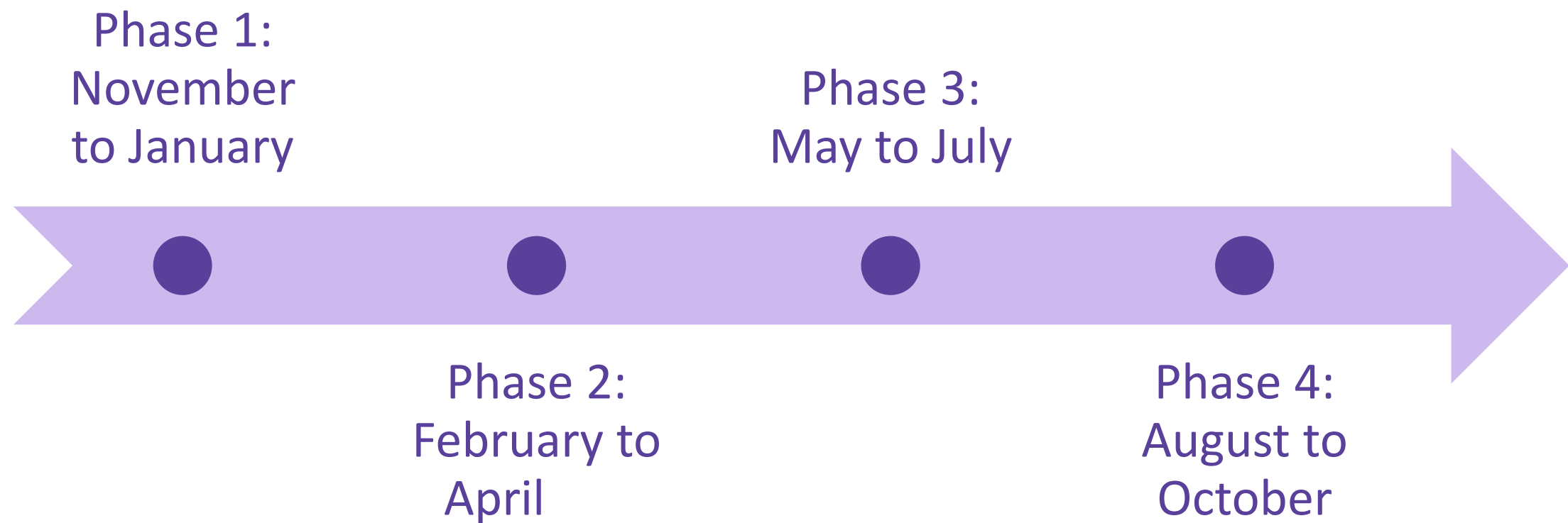
Primary Deliverables

Environmental
Scan



Toolkit

Timeline of the Project



Phases of the Project

Phase 1

- Conduct Landscape Scan
- Held first advisory committee meeting

Phase 2

- Conduct key informant interviews
- Analyze results
- Held second advisory committee meeting

Phase 3

- Using the environmental scan begin flushing out content of The Roadmap
- Held HMG affiliate work group meetings
- Held third advisory committee meeting

Phase 4

- Revise and finalize The Roadmap
- Held final advisory committee meeting
- Held HMG affiliate work group meetings
- Disseminate the Roadmap



Phase 1

Landscape Scan



Landscape Scan

Methods

- Passive form of data collection to better understand context of early identification in U.S. states and territories
- Included review of literature, websites, briefs, and reports
- Key words included *early childhood, data, data system, developmental monitoring, screening, referral, and early intervention, early childhood integrated data systems (ECIDS)*

Results

- Evidence of data collection efforts and data systems for screening, referral, and receipt of early intervention
- No evidence of activity or data collection for developmental monitoring

Advisory Committee Feedback

- Need to define developmental monitoring and differentiate it from screening
 - Identify what developmental monitoring is
 - Find examples of developmental monitoring
 - Where it is being documented
 - How it is recorded
 - How it is reported



Phase 2

Key Informant Interviews



Key Informant Interviews

- 13 Interviews
 - 19 individuals
 - 16 different types of early childhood programs
- Semi structured interview protocol to answer the following questions:
 - How is data on developmental monitoring collected?
 - How is data on developmental monitoring used?
 - How is data on developmental monitoring integrated with data on the other components of developmental promotion and early ?
 - Why is data collected and integration for early identification a priority?

Examples of Sub-Questions

Main Questions	Examples of Sub-Questions
How is data on developmental monitoring collected?	<ul style="list-style-type: none">• What data do you collect?• Is the data aggregated?• What are barriers and challenges?
How is data on developmental monitoring used?	<ul style="list-style-type: none">• How is the data connected to other data on early identification• Who sees the data
How is data on developmental monitoring integrated with data on the other components of developmental promotion and early ?	<ul style="list-style-type: none">• What did it look like to integrate this data?• What does it take to sustain integrated data?• What are the barriers to data integration?
Why is data collected and integration for early identification a priority?	<ul style="list-style-type: none">• What do you hope to learn?• What story do you want to tell with this data?

Data Points for Developmental Monitoring

The achievement of specific milestones

Asking parents about their child's development

Eliciting parent concerns about their child's development

Using parent questionnaires

Observing the child

Identifying risk factors (child born premature, smoking during pregnancy, exposure to lead, etc.)

Collecting information on child and family demographics

Results: Themes

Data Use (239)

System Integration(202)

Logistics (133)

Context of State, Territory,
or Locality (92)

Developmental
Monitoring (79)

Ever Changing System (79)

Data Use – Data Sharing and Integration

“currently our systems don’t talk to each other, but [memorandums of understanding] allow us to share data but usually hard copy...”

“On our playground there are 10 other agencies...making a systemic impact on child health. Take it from the perspective that every single one of those agencies was all tapped into the same system that was talking back and forth. We have a hard enough time keeping our systems that are only serving the purposes they are linked to working right.”

“When it comes to data there has to be a good reason for sharing...unless there is a specific reason for these systems to talk, if the reason is to identify trends or something to that extent it is just not going to be good...always the thought of big brother having way too much access”

Systems Integration & Family Engagement

“The parent engagement piece in our state now, we are first trying to connect with our community providers. All we have seen the last few years [is] this person is doing this, this person doing that. Through the last couple of years...we have all come together... we are all on this team together and trying to make everything one way that families do things. I think the very first part of this is that parent engagement and how we can get parents to understand the importance of developmental monitoring, so for them to really understand the monitoring piece is why they are going to understand...[the need for] developmental screening when they have a child 0-5”.

Logistics

Person on the Ground

- Designated people are needed to manage a programs workflow and data collection particularly when multiple programs are contributing to data collection
- One respondent noted the extensive amount of time needed on a weekly basis for communicating with partners to ensure they are up to date

Data Privacy

- Policies for protecting personally identifiable information vary across programs or states/territories
- Policies can facilitate or impede data sharing
- There are range of approaches for data privacy
- Barriers for data shar

State, Territory, or Local Context

- Program requirements vary by contexts
- Program requirements can facilitate data collection for early identification
- Examples
 - HealthySteps has stringent data collection requirements for screening to report to Zero to Three to maintain funding
 - DULCE family specialists review cases weekly with an interdisciplinary team of professionals and engage in monthly continuous quality improvement which allows them to look longitudinally at screening data
 - Parents as Teachers, an evidence-based home visiting program, use milestone checklists with families to monitor children's development

Developmental Monitoring

- No standard metric
- Not operationalized
- Not systematically defined across programs
- Types of data indicators
 - Milestone checklists
 - Encounters
 - Case notes
 - Asking about parental concerns
- Uncertainty about what type of data to collect
- Uncertainty if data is collected

Ever Changing System

- The history of a state or territory shapes policy, service delivery, and data collection
- Types of historical events
 - Prior data breaches
 - Development of new data systems
 - New laws
 - The pandemic
 - Evolution of data systems

“Everything is going to change... it will always be changing”

How is data on developmental monitoring collected?

- Data is collected as part of an interaction between a program or systems provider and the family
- A range of strategies from less formal to more formal efforts
- *However,....*
 - Instead of developmental monitoring many interviewees described screening
 - Many respondents noted monitoring occurs after screening and referral to follow up with families as an action rather than a component itself

How is data on developmental monitoring used?

- Continuous quality improvement
- Internal and external reporting
- Advocacy
- To support policy changes
- *However,....*
 - Most responses were about the other components of early identification
 - Do not collect disaggregated data and concerns expressed about equity
 - Data is not always used

How is data on developmental monitoring integrated?

- Not integrated
- Programs with control over a data system would be more likely to be able to integrate
- Barriers include:
 - Programs not “talking to one another”
 - Cost of data systems
 - Inconsistent funding

“It is all about funding...we only have funding to maintain what we have, not funding for all those great ideas”

“We are trying to learn how to be good stewards with the small funding we have to support and link as many families as possible in the state because we never know from season to season when this funding is going to dry up or change or be allocated in a different format...”

Why is data collection and integration for early identification a priority?

- Support young children and families
- Upstream approach to identify concerns
- Better outcomes for children over time

“...there are so many agencies vying to connect families with [resources], how does the resource you provide effect families, are they able to take advantage...is it what they truly need. There is a lot to be said about linking families to resources without having a clear picture of the landscape”

“The data story we are trying to tell is that all families need support and that [our program] is there to provide that support whether they know they need it or not. Telling the story of all families needing support, parenting is hard, and you don’t know what you don’t know...put families on a positive path in the face of challenges”

Advisory Committee Recommendations

- The goal of the project may not be about data collection, or a data system, but changing what is happening in the system
- Need a Theory of Change
- Need to define what developmental monitoring is
- Need to be explicit about what activities are involved in developmental monitoring

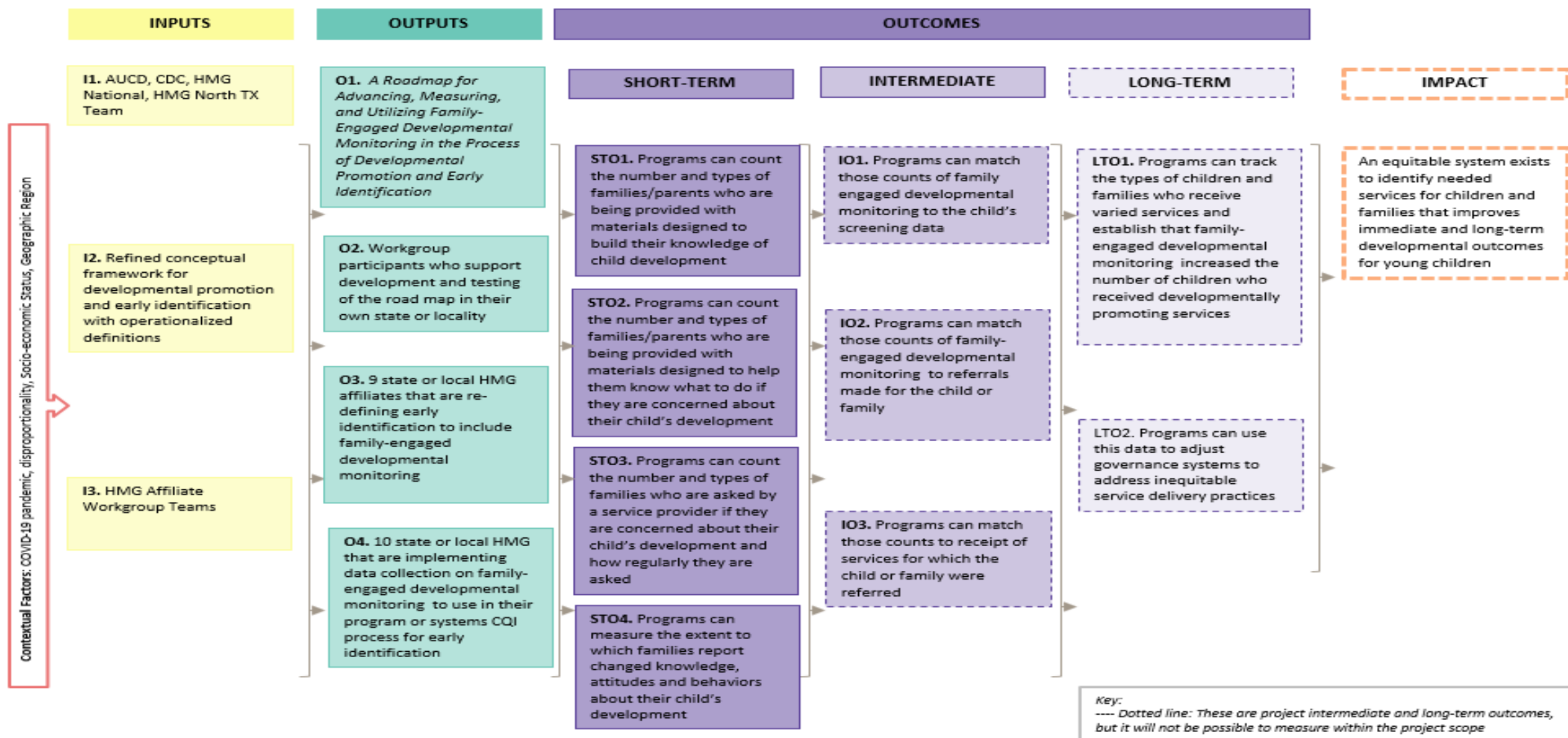


Phases 3 & 4

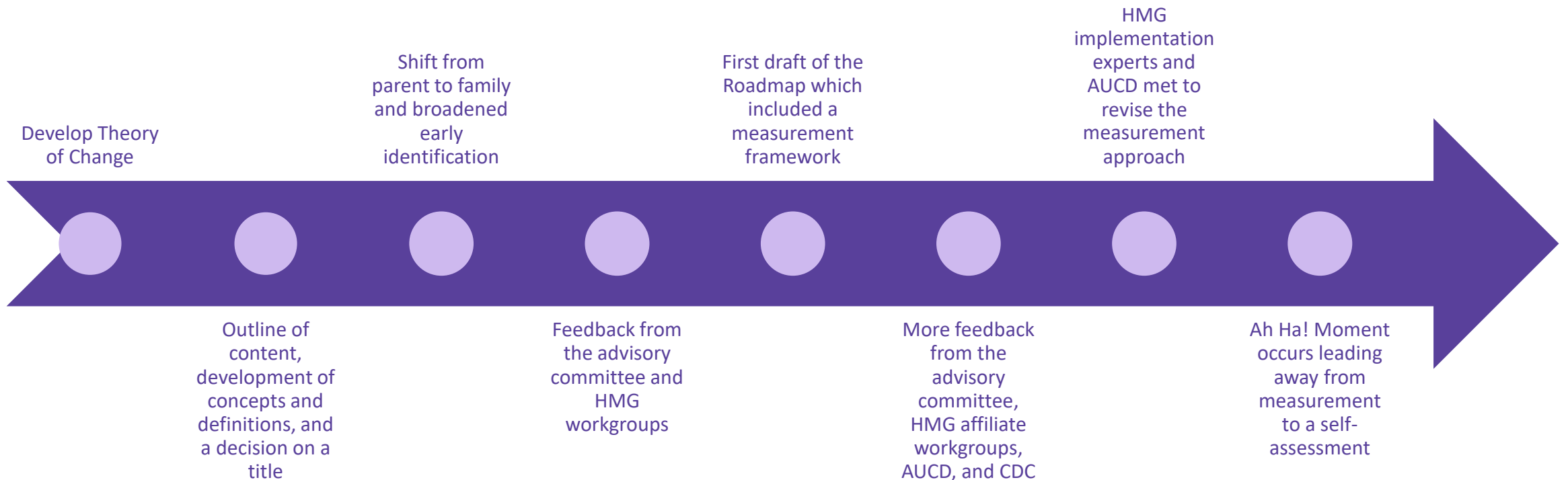
A Roadmap to Advance Family Engaged Developmental Monitoring



Theory of Change for Data Collection to Measure Impact of Developmental Promotion and Early Identification Processes



The Development Process for the *Roadmap*



The Purpose of the *Roadmap*

- Introduce, define, and describe family-engaged developmental monitoring (FEDM)
- Expand on early identification to include family-well being as critical to the process
- Ensure and asset-based approach for monitoring children's development
- Provide self-assessments for programs/providers and systems to gauge if they are doing FEDM

What is FEDM?

- FEDM occurs only during the interaction between a family and a provider
- The interaction has three attributes



Families are the expert on their child's development

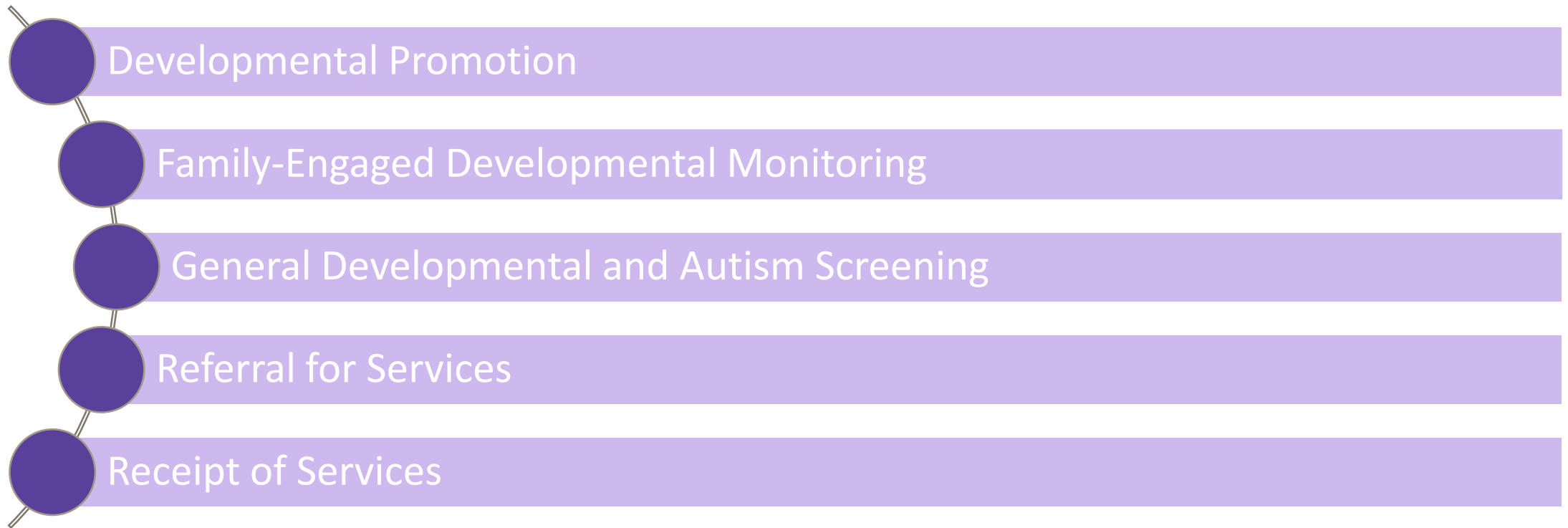


Holistic picture of child's development



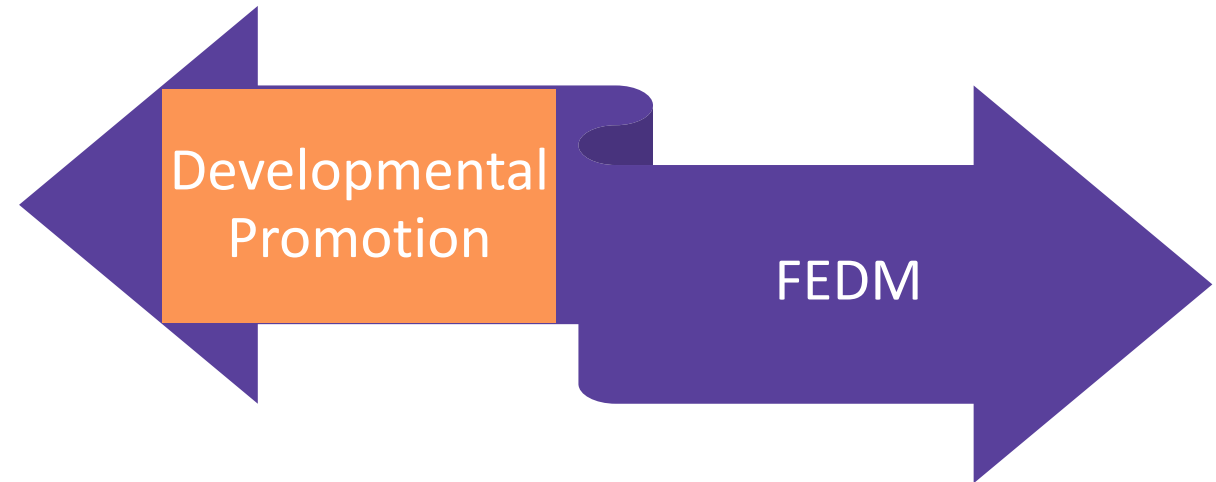
Development is discussed longitudinally

A Framework for Children's Healthy Development and Family Well-Being



Distinguishing between Developmental Promotion and FEDM

- The Roadmap supports a clearer delineation between developmental promotion and FEDM
- Developmental promotion promotes child development and shared knowledge between provider and family



Family and Provider Strategies

FEDM Attributes	Family Strategies	Provider Strategies
Families are regarded as the expert on their child's development	<ul style="list-style-type: none"> Families share observations and opinions about child's skills/behavior Families voice what healthy development means to them or what they feel their child needs right now 	<ul style="list-style-type: none"> Providers solicit concerns routinely Providers ask family opinion of their child's growth Providers identify parent priorities – for growth and support needs
Information is compiled to produce a holistic picture of the child's context	<ul style="list-style-type: none"> Families learn about factors that support or hinder development Families gather perspective from multiple adults or programs who interact with their children 	<ul style="list-style-type: none"> Providers gather information about family strengths, risk factors, etc. Providers ask about other program/provider insights (from families or directly from other providers)
Development is discussed longitudinally	<ul style="list-style-type: none"> Families note and reflect on their child's development over time (tools can help!) Families share how long any risk factors or concerns have been present Families revisit questions or progress with the same provider 	<ul style="list-style-type: none"> Providers ask families how the child's development or their own concerns have changed over time Providers re-engage with the family to revisit questions, concerns, or developmental progress

Examples of Items from the Self-Assessment for Early Childhood Programs & Providers

A Family-Engaged Developmental Monitoring Self-Assessment for Early Childhood Programs and Providers

- ✓ Each of the FEDM attributes below have critical questions to consider. Review each question and mark (✓) for those that are currently being achieved within your early childhood program.

Families are regarded as the expert on their child's development

Do you directly and routinely solicit parent priorities, concerns, and questions?

Does a family's priority for concerns or support shape your considerations for future support?

Information is compiled to produce a holistic picture of the child's context

Family-level risk factors, such as a child's underlying health conditions, family-level trauma, parental mental health or substance use?

Positive parenting practices, such as reading together, serve-and-return interactions, creating rich opportunities for play?

Development is discussed longitudinally

Do you solicit information on progress or concerns at every interaction/visit?

Do you ask families how they have seen their child progress over time?

Examples of Items from the Self-Assessment for Early Childhood Systems

A Family-Engaged Developmental Monitoring Self-Assessment for Early Childhood Systems

✓ Each of the FEDM attributes below have critical questions to consider. Review each question and mark (✓) for those that are currently being achieved within your early childhood system.

Families are regarded as the expert on their child's development

Are families' priorities, concerns, questions and feedback used to inform systems design and improvement?

Are families represented on your leadership or decision-making teams?

Information is compiled to produce a holistic picture of the child's context

Is your system able to collect, monitor, and analyze data related to the various social drivers of health listed below?

☐ Basic needs, such as food insecurity, access to medical care, unemployment and housing

Are your partnerships reflective of the priorities and needs of families in your community or state?

Development is discussed longitudinally

Is your system able to document, monitor, and analyze family responses longitudinally to questions such as:

☐ Family level goals and priorities?

Is data collected over time and used to inform the community about gaps, barriers, challenges, and opportunities to strengthen the early childhood system and advocate for community change?



Next Steps and Future Directions



Next Steps

Dissemination of the *Roadmap* by AUCD and HMG National

Dissemination of the *Roadmap* by advisory committee members

Present about the project and the *Roadmap* at the HMG Forum and Division of Early Childhood

Engagement with the parent centers to talk about how they can use the *Roadmap*



What is Needed for the Future

Audience
Guides

Case Studies

Developing
Measurement
Resources

Testing the
Framework

What Can You Do



1. Review the roadmap, its concepts and definitions



1. Consider the ways your system or programs are practicing Family-Engaged Developmental Monitoring by using the self-assessment tools!



1. Share with partners and your leadership teams

Questions





Act Early Response to COVID-19

August 2022



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